



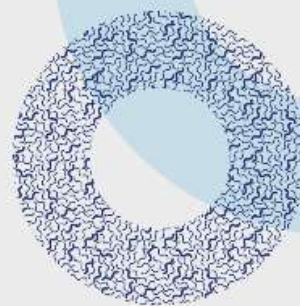
**Danish Diabetes and  
Endocrine Academy**

**Public and User Involvement  
in Danish Diabetes and  
Endocrine Academy (DDEA)  
Key Activities: Education,  
Networking, Communication  
& Grants  
- Why, How & When**

**10-11 May 2023**

**Storebælt Sinatur Hotel  
& Conference  
Østerøvej 121  
5800 Nyborg**

# Session overview



## **Day 1**

Session I

Session IIA, IIB

## **10 May 2023**

Setting the stage

Concurrent group work in funding and education

## **Day 2**

Session IIIA, IIIB

Session IV

## **11 May 2023**

Concurrent group work in communication and networking

Summary and next steps

# Programme

## 10 May 2023

- 09:00-09:30 Registration, coffee, tea and light breakfast
- Informal meet & greet
- Managing Director **Tore Christiansen**, DDEA (DK)
- Education & Networking Manager **Gretchen Repasky**, DDEA (DK)
- Communications Officer **Katrine Obel-Grønbæk**, DDEA (DK)
- Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)
- 09:30-09:40 Welcoming words and intention of the workshop
- Professor **Ingrid Willaing**, Steno Diabetes Center Copenhagen (DK)
- Session I**      **Setting the stage**
- Workshop Moderator: Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)
- 09:40-09:50 Introduction by the moderator
- 09:50-10:00 Danish Diabetes and Endocrine Academy (DDEA) & ambition for public and user involvement
- Education and Networking Manager **Gretchen Repasky**, DDEA (DK)
- 10:00-10:20 Public and patient involvement in Ireland: the PPI Ignite Network
- Professor **Sean Dinneen**, University of Galway (IE)
- 10:20-10:30 Questions & answers
- 10:30-10:50 Coffee & tea break

- 10:50-11:10 How PPI is a “must” in the UK in applications and research  
Psychologist **Michelle Hadjiconstantinou**, Diabetes Research Centre, College of Life Sciences, University of Leicester, (UK) and Reader in Diabetes and Primary Care **Kirsty Winkley**, Kings College, London (UK)
- 11:10-11:20 Questions & answers
- 11:20-11:40 What have we learned from five years of experience with user involvement in cancer research?  
Professor **Helle Pappot**, Rigshospitalet and Institute for Clinical Medicine, University of Copenhagen (DK)
- 11:40-11:50 Questions & answers
- 11:50-12:05 Let’s turn it upside down: inviting researchers to the real world instead of the other way around  
Chair of the Board, **Søren Dixen**, Maskine Maskine Amager (DK)
- 12:05-12:10 Questions & answers
- 12:10-12:30 Introduction to the small group sessions  
Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)
- 12:30-13:15 Lunch & informal networking

**Session II Concurrent small group sessions**  
**A. Public involvement in funding applications & decisions**  
**B. Public involvement in researcher education**

**Session IIA Public involvement in funding applications & decisions**  
Location: Askø  
Facilitator: Professor **Ingrid Willaing**, Steno Diabetes Center Copenhagen (DK)

13:15-13:25 Introduction by the facilitators

13:25-13:40	Options to involve users in research funding decisions PhD Student <b>Lauge Neimann Rasmussen</b> , University of Copenhagen & Steno Diabetes Center Copenhagen (DK)
13:40-13:45	Questions & answers
13:45-14:00	Involving young adults in research: Lessons learned from the D1 Now study Postdoctoral Researcher <b>Eimear Morrissey</b> , University of Galway (IE)
14:00-14:05	Questions & answers
14:05-14:30	Coffee and tea break & informal discussion of the presentations
14:30-16:15	Small group work Four groups will focus on recent calls for DDEA PhD Scholarships and Postdoctoral Fellowships
16:15-16:35	Break with snacks, return to plenary

## Session IIB Public involvement in researcher education

Location: Agersø

Facilitators: Researcher **Annemarie Varming**, Steno Diabetes Center Copenhagen (DK) and Experience Expert **Walther Jensen** (DK)

13:15-13:25	Introduction by the facilitators
13:25-13:40	Experiences with involvement of users in conferences & workshops – from planning to execution Experience Expert <b>Walther Jensen</b> (DK)
13:40-13:45	Questions & answers
13:45-14:00	Challenges and experiences with user involvement in a PhD course Clinical Nurse Specialist <b>Annesofie L. Jensen</b> , Steno Diabetes Center Aarhus (DK)

14:00-14:05	Questions & answers
14:05-14:30	Coffee and tea break & informal discussion of the presentations
14:30-16:15	Small group work Four groups will work on a vignette based on an upcoming DDEA event and suggestions of general principles for public involvement in DDEA researcher education activities
16:15-16:35	Break with snacks, return to plenary

16:35-17:35	Reporting from small group work Chief Consultant <b>Ulla Møller Hansen</b> , Center for Patient Involvement (CPI) (DK)
17:35-17:40	Closing words of Day 1 Chief Consultant <b>Ulla Møller Hansen</b> , Center for Patient Involvement (CPI) (DK)
17:40-19:00	Hotel check-in
19:00	Dinner

# Programme

## 11 May 2023

07:00-08:30 Breakfast & hotel check-out

08:30-09:00 Summary of Day 1, introduction to the small group sessions of Day 2

Workshop Moderator: Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)

### Session III Concurrent small group sessions

**A. Public involvement in the communication of research**

**B. Public involvement in networking**

#### Session IIIA Public involvement in the communication of research

Location: Askø

Facilitators: Researcher **Annemarie Varming** and Professor **Ingrid Willaing**, Steno Diabetes Center Copenhagen (DK)

09:10-09:20 Introduction by the facilitators

09:20-09:40 How can we facilitate active partnership in public engagement? Perspectives from the museum

Associate Professor & Curator **Louise Whiteley**, Medical Museion and Novo Nordisk Foundation Center for Basic Metabolic Research (CBMR), University of Copenhagen (DK)

09:40-09:45 Questions & answers

09:45-10:00 DDEA communications, plans and ambitions  
Communications Officer **Katrine Obel-Grønbaek**, DDEA (DK)

10:00-10:25 Coffee and tea break, informal discussions

10:25-12:05 Small group work

Four groups will discuss PPI in DDEA communication: who, what, where, when and how

12:05-12:25 Break with snacks, return to plenary

### **Session IIIB Public involvement in networking**

Location: Romsø

Facilitators: Clinical Nurse Specialist **Annesofie L. Jensen**, Steno Diabetes Center Aarhus (DK) and Experience expert **Walther Jensen** (DK)

09:10-09:20 Introduction by the facilitators

09:20-09:30 The network as a tool

Chairperson **Tine Filges**, Type1 – Thinktank for Diabetes (DK)

09:30-09:35 Questions & answers

09:35-10:00 Discussion & group work

How could researchers create a network with user-groups or persons who are members of a user-group?

10:00-10:25 Coffee and tea break, informal discussions

10:25-10:35 Collaboration between DFOI and professionals

Social Worker, Lecturer **Rune Bang Mogensen**, Danish Association for Osteogenesis Imperfecta (DFOI) (DK)

10:35-10:40 Questions & answers

10:40-12:05 Discussion & group work

Experiences, ideas and solutions to creating networks with patient associations

12:05-12:25 Break with snacks, return to plenary



12:25-13:25 Reporting from small group work  
Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)

**Session IV Summary & next steps**

Workshop Moderator: Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)

13:25-13:50 Summary and reflections on the why, how and when  
Chief Consultant **Ulla Møller Hansen**, Center for Patient Involvement (DK)

13:50-14:00 Next steps and closing words  
Managing Director **Tore Christiansen**, DDEA (DK)

14:00 Lunch bags to go

## Anticipated Outcome of the workshop

The workshop is expected to make significant contributions to an inspiration catalogue containing guidelines on how public and user involvement can be applied to the key activities of the DDEA.

'Pseudo involvement' - involving users simply because 'you have to do it' - must be prevented.

The catalogue will be specific, focused and sincere, representing positive contributions for both researchers and users

# Organising Committee of the Workshop

**Annemarie Varming**, Steno Diabetes Center Copenhagen (DK)

**Annesofie Lunde Jensen**, Steno Diabetes Center Aarhus (DK)

**Helle Max Martin**, Steno Diabetes Center Copenhagen (DK)

**Ingrid Willaing**, Steno Diabetes Center Copenhagen (DK)

**Søren Dixen**, Maskine Maskine Amager (DK)

**Walther Jensen**, patient advocacy (DK)